



Coming of Age in Massachusetts

A LEGAL RESOURCE GUIDE | 3RD EDITION

*A legal guide for individuals
with developmental disabilities
and their families on transitioning
to adult services*

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WELCOME!

Planning is a key ingredient in any successful journey. The journey from special education to adult services inevitably occurs due to the mere passage of time. Making that journey as smoothly and successfully as possible requires a knowledge of what to expect and being prepared to make important planning decisions. The purpose of this legal guide is to provide you with information about the journey. Hopefully you will find it helpful whether you are years away from adult services or the transition is imminent.

In the following pages, you will find information about the legal consequences of turning 18 years old; important benefits from the state and federal governments; options to assist in personal, financial and health care decision making and the importance of special needs planning by parents and other family members.

COMING OF AGE IN MASSACHUSETTS

3RD EDITION
ACKNOWLEDGMENTS

It is now six years since the first edition of *Coming of Age* was published. Since that time, I've worked with hundreds of families and individuals who have transitioned from the world of special education to the adult services world. In doing so, I have witnessed great triumphs where "all the pieces fit," including obtaining needed government resources; great collaboration among interested parties including transition coordinators, parents, individuals and planners; and appropriate legal planning as described in this resource guide. Unfortunately, this hasn't been the case in all instances. Government resources are still far from predictable and sufficient. Transition planning is too often treated as an afterthought. The level of frustration and anxiety is high as the age of emancipation, age 18, approaches as well as when the loss of special education entitlement looms large at age 22.

I hope this third edition provides some degree of direction and support to individuals and their families as they approach these two milestone dates. I would like to acknowledge the advocacy and dedication of the hundreds of individuals and families I've worked with who have traveled this road to legal emancipation and to the adult services world. And I dedicate this edition to the pioneering efforts of so many parents and individuals who have demonstrated a commitment to self-determination, a willingness to advocate for change when change is warranted, and an enduring optimistic view toward planning a meaningful and fulfilling life.

Frederick M. Misilo, Jr.
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LEGAL EMANCIPATION & TURNING 18

When a person turns 18 years of age, in the eyes of the law, that person is presumed to have the capacity to make informed legal, financial and health care decisions. In other words, when a person reaches the age of 18 years, parents are no longer able to make decisions on their son's or daughter's behalf. This also means that, in most circumstances, parents are not entitled to receive personal information about their son or daughter from health care providers, human service professionals, educational services and others.



Of course, not everyone is able to make the best decisions immediately upon turning 18 years old. In fact, most people can use some help in making informed decisions throughout their lifetime. In some cases, individuals may need protection from making really bad decisions that could result in financial loss, serious injury or worse. In the next section, you will read about options that need to be considered when a person with a developmental disability needs some help in personal, financial and/or health care decision making.



OPTIONS FOR PERSONAL, FINANCIAL & HEALTH CARE DECISION MAKING

From Least to Most Restrictive

1. Special Bank or Custodial Accounts

Joint bank accounts can be created to prevent rash expenditures. Arrangements can be made for a person's benefit check, such as Social Security Disability Income ("SSDI") or Supplemental Security Income ("SSI"), to be sent directly to the bank for a direct deposit. Additionally, a permanent withdrawal order can be arranged with the bank, authorizing the bank to send certain sums of money on a regular basis to a specified party, such as the landlord or the person who is disabled, for pocket money, thus providing structure to allow for budgeting and money management. Some financial planners and attorneys will assist a client with payment of regular monthly expenses through the use of a custodial account that operates similarly to a permanent withdrawal order. Through the use of a custodial account, payment can be made for goods and services on a regular and/or an as-needed basis.

2. Trusts

A trusts may be an appropriate alternative to conservatorship. A trust is a legal plan for placing funds and other assets in the control of a trustee for the benefit of an individual. Trusts for the benefit of a person who has a disability should be established with the help of a lawyer experienced in wills and trusts and familiar with the law relating to government disability benefits. A trust set up without regard to the eligibility laws may disqualify a person who is disabled from MASS Health, SSI and other important means-tested government benefits.

3. Representative Payee

For persons receiving government benefit checks, consider obtaining a representative payee to manage these funds. Benefit checks are sent to the representative payee, who manages them and spends them for the benefit of the individual with a disability. The representative payee has authority over only income from the particular checks for which she is payee. Representative payees for recipients of Supplemental Security Income are required to file annual reports to the Social Security Administration. Additional information on the Representative Payee Program of the Social Security Administration can be obtained at the website, www.socialsecurity.gov/payee.

4. Durable Power of Attorney for Property

A durable power of attorney (“DPOA”) for property is useful when a person has a mild or moderate incapacity and is capable of choosing a trusted person to handle his/her money. The DPOA is a legal document in which a person termed “the Principal” gives another person, “the Attorney-in-Fact,” the legal authority to handle his or her financial affairs. A DPOA is revocable. This means that the DPOA can be revoked at any time by the Principal. Also, the Principal who creates the DPOA retains decision-making authority over his or her property. A benefit of a DPOA is that it is a flexible arrangement for a person who needs some assistance in decision making. At the same time, a drawback can be that a Principal with a quick temper or who acts impulsively without thinking things through may remove the Attorney-in-Fact at a time when he or she is needed the most.

5. Appointment of an Advocate

Individuals may appoint another person to act as their advocate in educational, adult services or health related matters. This advocate can obtain documents, attend meetings and generally speak up for an individual in important ways. This legal arrangement is similar to a DPOA except that the authority of the Advocate is limited to specified areas.

6. Health Care Proxy

A health care proxy is a legal document that enables a competent individual (the Principal) to designate a health care agent to make health care decisions should the Principal become unable to make or communicate health care decisions. The health care agent is permitted to make all health care decisions, including decisions about life-sustaining treatment. The proxy must be a written document that is signed by the Principal and witnessed by two adults. The Principal may revoke the proxy at any time and in any manner that demonstrates specific intent to terminate the power. A health care proxy goes into effect when the Principal’s doctor determines in writing that the Principal can no longer make or communicate health care decisions. If the Principal regains capacity to make or communicate health care decisions, then the authority of the health care agent to make these decisions ends.

7. Conservatorship

Conservatorship should be considered for persons who are unable to make informed financial decisions and who have income from sources other than government benefit checks. A conservator handles only financial affairs. The court may appoint a conservator if the person is unable to properly care for his or her property. Physical incapacity is also a legally sufficient reason for appointing a conservator, provided the person agrees to the appointment. The Massachusetts Uniform Probate Code places many requirements on conservators. Conservators must act in the best fiduciary interests of the individual, involve the protected person in decision making, and work to develop or restore the individual’s ability to manage his own affairs. The court also monitors the performance of conservators by reviewing accounts and plans created by the conservators.

8. Guardianship

Guardianship is an option for persons who are incapable of making decisions about their personal affairs. Massachusetts has adopted the Uniform Probate Code (“the Code”), which requires evidence of incapacity and disability rather than incompetence. This incapacity or disability evidence helps to focus on functional limitations. A Clinical Team Report (“CTR”) must be filed with a guardianship petition. The CTR is a detailed report on the functional ability of the person who is subject to the guardianship proceeding that must be signed by a physician, licensed social worker and licensed psychologist. The CTR assists the court in evaluating the need for guardianship. The Code favors limited guardianship rather than a full or all-encompassing guardianship. The Code also creates a requirement that guardians file an annual written report, called a Care Plan Report, covering important areas of life such as living arrangements (including planned changes) and services. Also, the Code requires annual visits by the guardian, and there are requirements that the guardian must disclose and follow a health care proxy previously created by the individual. The guardian must follow the wishes as provided for in the health care proxy. The guardian cannot revoke the health care proxy without a court order.



As you can see, there are a number of options for personal, financial and health care decision making. The best practice is to explore least restrictive options first prior to moving toward more restrictive options. By doing so, an individualized plan of support can be provided without unduly restricting a person’s right to make decisions he or she may be competent to make on his or her own.

Legal Capacity to Sign Legal Documents

Determining whether someone has the mental capacity to sign a durable power of attorney, health care proxy and advocate appointment is necessary in order for those documents to have any legal effect. There is no bright-line test to determine whether someone has what is referred to as contractual capacity. It requires, in essence, an ability to understand the nature of the transaction and quality of the transaction, with an understanding of its significance and consequences. Very often, it is helpful to seek the advice of a qualified mental health professional in determining whether someone has the requisite capacity to sign legal documents. It is advisable to have an evaluation with a licensed mental health professional to determine whether some less restrictive alternatives to guardianship are a viable option.

Don’t Forget to Register with the Selective Service

All male U.S. citizens who are 18 through 25 years of age must register with the Selective Service. Men with a disability who are not continually confined to home, a hospital or an institution must register. Even if a disability would disqualify a man from military service, he still must register with the Selective Service. Selective Service does not presently have authority to classify men, so even men with an obvious disability must register now, and if needed, classifications would be determined later.

TRANSITION TO FEDERAL GOVERNMENT BENEFITS

Government Benefits Based on Financial Need

Two important programs for persons with disabilities are SSI and Medicaid. In Massachusetts, Medicaid is referred to as Mass Health. Upon attaining the age of 18 years, individuals are eligible for SSI and Medicaid even if they are living with their parents and without the parents' assets and income being deemed to them. It is important for parents to realize that eligibility for SSI and Medicaid may be critical to an individual who is disabled because SSI and Medicaid eligibility is often necessary for adult services such as case management; job training; individual and family support services including respite and attendant care; specialized vocational services; protection and advocacy services; and residential services. Given the range of services that are presently available through SSI and Medicaid and those that may be available in the future, it is important to be aware of the financial eligibility criteria to qualify for these two programs.

Two important programs for persons with disabilities are SSI and Medicaid.

Eligibility for SSI

Eligibility for SSI requires that the person be aged, blind or disabled and that the individual have limited income and resources according to the guidelines of the program. Income is defined as "the receipt by an individual of any property or service which he can apply, either directly or by sale or conversion, to meet his basic needs for food and shelter." The SSI regulations specifically include inheritance and gifts as income. SSI regulations further state that property is considered a resource if the claimant has the right, authority or power to liquidate the property.

An individual is allowed up to \$2,000 in resources before being disqualified from receiving benefits. The recipient is also allowed to own a home, one car (regardless of its value, if it is used to transport the recipient or a member of the recipient's household) reasonable household goods and personal effects, and a life insurance policy if the total face value does not exceed \$1,500.

Impact of Child Support Payments on Supplemental Security Income Financial Eligibility

Child support payments made to a custodial parent on behalf of an adult son or daughter will be counted by the Social Security Administration as unearned income received by the SSI applicant. This will reduce and, in some instances, eliminate SSI eligibility. To avoid this result, it is necessary to obtain an irrevocable court-ordered assignment of the child support allocable to the SSI applicant to a special needs trust that meets the requirements of 42 U.S.C. 1396p. This is best handled prior to the application for Supplemental Security Income.

A Note About Parents' Health Insurance Coverage

Some parents may feel that they do not have to be concerned with federal medical assistance because their adult child is covered with a private health insurance policy. Often the coverage in programs that insure persons who are disabled is minimal, and the cost for private medical coverage may be prohibitive in the future. In some cases, while the child presently has medical insurance, his or her medical coverage may terminate upon the death of a parent or the loss of employment or retirement of the parent.

Many parents are not aware that they can continue their group plan health care coverage for their dependent adult child after their child graduates or leaves school. You will need to check with your human resources department to see if your company health insurance plan has this option available.

Most companies require that you notify them within three months of your child's 19th birthday that he or she is disabled and is dependent on you for care. If you do not notify your health insurance carrier of your child's special needs, the carrier may drop your child from your coverage.

Impact of the Affordable Care Act ("ACA")

The ACA has a major impact on individuals with intellectual and developmental disabilities. It reforms private health insurance by eliminating pre-existing condition exclusions for individuals under the age of 19. Effective in 2014, this ban will also apply to adults. A pre-existing condition is one that existed before the date of enrollment for health insurance coverage. The ACA also bans annual and lifetime limits in health plans and insurance policies. The ACA also ends the practice of rescission (when insurance coverage is retroactively canceled when an individual develops an expensive health condition). Dependent coverage has been expanded under the ACA, which enables dependents to continue to be covered under their parents' health insurance plans until age 26. These are some examples of the benefits of the ACA. There are numerous other benefits, such as the creation of health insurance exchanges for individuals and small employers to purchase insurance, improvement to the appeals process and expansion of essential benefits for qualified health benefit plans.

Federal Benefits NOT BASED on Financial Need

The major income and insurance programs in this category are SSDI and Medicare. A child of a person who is retired, disabled or deceased can collect monthly cash benefits based on the parents' earnings previously paid into Social Security provided that the child's disability began before the age of 22 and he or she is unmarried and is dependent for support on the parent who is retired, disabled or deceased.

Disability is defined as "the inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months."

A person who receives Social Security disability benefits for 24 consecutive months is entitled to Medicare. The advantage of Social Security benefits is that the benefits are not reduced or affected by the person's assets.

TRANSITION TO ADULT HUMAN SERVICE SUPPORT SYSTEMS

We wish to gratefully acknowledge that this section is derived primarily from "The Road Forward" (2nd Edition, May 2007) published by the DDS Central Middlesex Area Office.

WHAT is Chapter 688?

Chapter 688 is a law enacted in 1983 to provide a two-year planning process for young adults with severe disabilities who will lose their entitlement to special education at the age of 22 or at the time of graduation from high school, whichever comes first. The law creates a single point of entry into the adult human services system.

WHO is eligible for Chapter 688?

To be eligible for Chapter 688 services, a person must:

- Be receiving special education paid for by the Commonwealth of Massachusetts,
- Need continuing habilitative services at the time of turning 22 or graduating from special education, and
- Be unable to work competitively (without specialized supports) for more than 20 hours per week at the time of leaving school.

An individual is automatically eligible for Chapter 688 if receiving SSI, SSDI, or registered with the Massachusetts Commission for the Blind.

HOW is a 688 referral made?

Only the local school system, also known as the Local Education Authority or LEA, can make a 688 referral. The referral must be made while the student is still in school. The local school system typically decides which human service agency might best meet the student's needs as an adult and sends the referral directly to that agency. If an individual is being referred to DDS, the referral typically is sent directly to one of the DDS Area Offices. If a student or parent feels that a 688 referral has not been made but should have been, they should contact the Special Education Department at the school, or the Director of Special Education services for the school system.



WHEN should a 688 referral be made?

Chapter 688 requires the school system to make the 688 referral two years before a student graduates or turns 22, whichever is earlier. In order to facilitate the planning process, DDS prefers to have the 688 referral even earlier than required by Chapter 688. DDS suggests that referrals be made at age 18 to coincide with DDS adult eligibility age requirements. Referrals that are made less than 2 years until graduation do not afford adequate planning time to assist a student in the most meaningful way possible. Students or families who are concerned about the timing of a 688 referral should contact both the school system and the local DDS Area Office, if they feel DDS would likely become the Transitional Agency.

If a student is already known to DDS, is a 688 referral still necessary?

YES. Even though some individuals with intellectual disabilities receive DDS services as children, a referral should still be made. The 688 referral starts the DDS planning process for the individual student.

What is the "SPED DATE" and why is it important?

The special education date (or "sped date") is the date on which a student is planning to leave special education and school. Typically, the sped date is either the student's expected date of graduation or 22nd birthday. The sped date is used in the 688 referral process as the reference date for planning. Students leaving on short notice in advance of the sped date specified on the 688 referral may not have the benefit of adequate planning time to assist with a smooth, well-planned transition.

What happens if a student leaves school without a 688 referral?

If a student leaves school without a 688 referral being made, the student is not eligible for planning through 688. The student can still apply to DDS or other state agencies serving adults at any time as any citizen could.

What is the Transitional Agency (TA)?

The Transitional Agency (TA), sometimes referred to as the Lead Agency, is the state agency that receives the 688 referral. It is the agency that the local school system feels will best meet the student's future needs as an adult. The TA is responsible to assist the individual in planning to move from special education services into adult life. DDS is one such agency. Other Transitional Agencies include the Department of Mental Health and the Massachusetts Rehabilitation Commission.

DDS 688 TRANSITION COORDINATOR

What is a DDS Transition Coordinator?

A DDS Transition Coordinator, sometimes called the “688 Coordinator,” is a case manager who works at the local DDS Area Office. The Transition Coordinator’s case load consists of individuals aged 18-22 who have been found eligible for adult supports through DDS. The Transition Coordinator is the individual’s primary link to information and assistance from DDS during the transition from special education to adult life. The Transition Coordinator will help the individual and family understand what DDS can offer and assist with identifying and securing requested supports, subject to prioritization for those supports. Following graduation and transition into adult supports, an individual’s case will be transferred to an Adult Service Coordinator within the Area Office.

Who is eligible for adult supports from DDS?

A person, 18 or older meets the criteria for eligibility for services and supports provided, purchased or arranged by the Department if the individual:

1. is domiciled in the Commonwealth of Massachusetts
2. is a person with an intellectual disability as defined in 115 CMR 2.01 (this information can be found under the “regulations and policies” link at www.mass.gov/DDS)

What is the application process?

Application Process: The application process is initiated by sending an application form (Application for DDS Eligibility) to the DDS Eligibility Team. This form contains basic information about the applicant that enables a Regional Eligibility Specialist to contact the applicant to arrange an interview. The Regional Eligibility Team may receive telephone requests for eligibility determination and may complete the application form via telephone conversation.

Intake Process: When the application is received, an eligibility specialist from the Regional Eligibility Team will contact the applicant, guardian or referral source within 10 days of receipt of a completed application form to arrange for an intake interview. This interview can take place at the DDS Regional Office, the Area Office or other location. The intake process generally consists of the initial interview, the gathering of relevant information that may include requests for additional assessments or testing, and a clinical assessment that assists the DDS to identify needed resources.

DDS ELIGIBILITY PROCESS DOMICILE/CATAGORICAL

Eligibility Determination: The applicant or guardian is responsible for obtaining all relevant information needed to determine eligibility and must make every reasonable effort to ensure that the information is received by the Department in a timely manner. When all information is gathered and assessments completed, the Regional Eligibility Team Psychologist conducts a review and makes the determination decision after conferring with members of the Eligibility Team.

The Regional Eligibility Team is asked to make a determination within 60 days. If no final determination can be reached after 60 days due to incomplete information, the DDS may extend the process for an additional 60 days. After 120 days, the Regional Eligibility Manager will send a formal decision letter based on the information that has been made available to DDS. This decision is communicated to the applicant or his/her guardian and to the appropriate DDS Area Office.

Determination of Needed Supports for Eligible Individuals:

MASSCAP

To determine whether a requested support or service will be given to an individual, DDS uses a system called the Massachusetts Association for Community Action (“MASSCAP”). MASSCAP is a clinical assessment tool that determines the need for a particular service. The MASSCAP consists of three assessment tools. One tool is called the Inventory for Client and Agency Planning (“ICAP”). ICAP is an automated tool that assesses an individual’s adaptive functioning. Its scoring is empirical and gives a functional perspective on the individual. The areas assessed by the ICAP are: Motor Skills, Social and Communication Skills, Personal Living Skills, and Community Living Skills. An individual tested using ICAP is given a score ranging for zero to three points. Zero points meaning never, or rarely does well in that area, while three means does very well in that area. This information is then entered into the ICAP application to determine the total ICAP score.

Another tool of the MASSCAP is the Consumer and Caregiver Assessment (“CCA”). The CCA allows DDS to analyze the resources and supports that are currently in place for the individual, provide a source of information about what could be put in place to further assist the individual, and provide information to assist in evaluating the caregiver’s capacities. It is a combination of descriptive and numerical information. The CCA looks at the current caregiver and his or her ability to continue to provide support in a manner that keeps the individual safe from harm.

A third tool used by MASSCAP is the application of clinical judgment through the use of other assessments and consideration of other relevant factors concerning the individual. An assessor may seek additional information to determine the individual’s need for services. These supplemental assessments can range from psychological tests to additional functional behavioral tests that may better define an individual’s need. The decision to include additional assessments is strictly at the Department’s discretion.

Once the MASSCAP has been completed and the individual is found to have a need for service, the next step in the process is to determine the prioritization level for that service within existing resources. Prioritization is an administrative tool that separates priority into three groups: Priority 1, Priority 2 and No Priority. Priority 1 means that provision, purchase or arrangement of supports available through the Department is necessary to protect the health or safety of the individual or others. Priority 2 means that provision, purchase or arrangement of supports available through the Department is necessary to meet one or more of the individual's needs or to achieve one or more of the needs, identified in his or her Individual Service Plan. Under Priority 1 needs the service planning should be initiated and services should be arranged or provided within 90 days. Under Priority 2 needs, the Department should be engaged in active planning with the family or individual within 90 days and services should be provided or arranged within 12-18 months. This time period, however, is dependent on funding. A No Priority determination means that services are not considered a priority for funding by DDS.

Appeals

Individuals have the right to appeal any findings contained in the eligibility or prioritization letter within 30 days of receiving the letter and have the right to a Fair Hearing before an impartial hearing officer.

Adult Family Care—An Option for Families

Persons with a disability aged 16 years old or older are eligible for Adult Family Care. This program permits family members, often a parent, to be a paid caregiver to another family member with a disability. In order to qualify, a person with a disability must undergo an assessment to determine whether he or she is unable to live alone and needs daily assistance with one or more activities of daily living. An important requirement for paid care providers is that they may not be legally responsible for the person to whom they are providing care. In the case of a parent, they must be providing care to an emancipated son or daughter for whom they are not guardian. There are two levels of care depending on the degree of support the individual needs. Caregivers are paid a salary, receive support and training from the Adult Family Care provider agency, and receive home visits from a social worker and a nurse, and respite. For more information, go to www.DisabilityInfo.org.

SPECIAL NEEDS PLANNING BY PARENTS

As noted throughout this handbook, it is likely that at some point in his or her life, a person with a disability will need government benefits such as SSI, Medicaid, residential support, job training and other support services. Parents need to plan so that their son or daughter can maximize opportunities to receive government benefits and services. Parents need to realize that without careful planning, an inheritance may make their child ineligible for benefits that can be far more valuable than the inheritance. In some cases, the more a person inherits, the worse off he or she may be. Government benefits are important because it is seldom possible for the average family to leave sufficient funds to provide sufficient services and supports. The cost of services and supports varies tremendously depending on the area in which the individual lives and the nature and degree of the individual's disability. It is difficult to predict what these costs will be 20 or 30 years from now.

Parents have an opportunity to supplement government benefits with family assets through careful special needs planning. There are a variety of approaches to consider, including the creation and funding of a supplemental needs trust, also called a special needs trust, which holds assets for the benefit of a person and which does not affect that person's entitlement to needs-based government benefits such as SSI or Medicaid. Upon the death of the beneficiary, the assets held in a supplemental needs trust funded by the beneficiary's family are distributed to those persons identified in the trust and not the government.



IMPLICATIONS FOR FAMILIES REGARDING SPECIAL NEEDS PLANNING

Special needs trust expenditures can include but are not limited to:

- Additional physician visits (*over the Medicaid limit*)
- Appliances
- Bicycle, fitness equipment, personal trainer
- Bottled water
- Bus or train pass
- Cab scrip
- Cable TV bill
- Car/van: fuel, repairs, maintenance, insurance
- Cell phone
- Club dues
- Computer, Internet service, software, training, repairs
- Curtains, blinds, drapes
- Dental work, eyeglasses, hearing aids (*batteries not covered*)
- Dermatology not covered by Medicaid
- Drugs unavailable through Medicaid (*non generic*)
- Entertainment, movie or theater tickets
- Furniture
- Haircuts, manicures, pedicures and other salon services
- Health club membership
- Hobby supplies
- Housecleaning/maid service
- Incontinence supplies and equipment
- Laundromat/dry Cleaners
- Legal fees/guardian fees
- Lessons, classes, or college tuition and fees
- Linen
- Massage, acupuncture /acupressure, Rolfing and other alternative treatments
- Musical instruments

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- Nonfood grocery items, such as: *laundry soap, bleach, tissues, household cleaning products, paper towels, napkins, deodorant, soap, personal hygiene products*
 - Orthopedic shoes/podiatry
 - Over-the-counter medications
 - Oversight, monitoring and advocacy
 - Painting and music therapy
 - Payment of private health insurance premiums
 - Personal attendant services beyond Medicaid limits
 - Pets, pet supplies/food, pet care (*veterinarian bills, etc.*)
 - Private counseling
 - Record/book clubs
 - Rehabilitation and physical therapy beyond Medicaid limits
 - Respite care
 - Telephone bill or phone card
 - TV, VCR, DVD player, stereo
 - Vacation
 - Vitamins, herbs
 - Wheelchairs not covered by Medicaid; repairs, driving gloves

CAUTION: Do not distribute funds directly to the beneficiary. The above goods and services must be paid directly from the trust to the vendor or service provider.

PREPARING A LIFE-PLANNING DOCUMENT FOR YOUR DISABLED FAMILY MEMBER

A life-planning document, sometimes called a "letter of intent" or "letter of instructions," aims to provide critical information to future service providers and trustees.

Such a document can contain the following information about:

- Personality characteristics and personal preferences
- Family members
- Medical history, list of physicians, and other individuals and organizations providing support and services
- Friends, pets, favorite foods, likes and dislikes, and hopes and expectations

You should develop a life-planning document when it is likely that your son or daughter will live outside your home sometime in the future and will require a good deal of support and services to maintain and enhance his or her quality of life.

A life-planning document is important to have because many people with cognitive or psychological impairments may be unable to accurately convey pertinent facts and information about themselves to others. The life-planning document gives you an opportunity to communicate your perspective on and knowledge of your family member regarding a wide range of topics. Combined with your disabled family member's self-determination, the life-planning document contains the core considerations that providers should heed when providing support and services.

The amount of time and energy required to prepare a life-planning document varies widely, depending on how much information you want to include and whether you plan to write it by hand or on a computer. Generally speaking, count on it taking six to eight hours. Fletcher Tilton PC has developed a life-planning document template to help parents begin this process. This template can be found on our website www.fletchertilton.com. The initial effort can be considerable and daunting as you try to think of everything to include. Rest assured that updates are usually much easier. We recommend that you update the life-planning document at least once a year—perhaps around the birthday of your disabled family member. Using his or her birthday may help you remember that it is time to update the document. Time has a way of flying, and without a trigger date to help you remember, you may forget to update the plan.

If you find it difficult to write a life-planning document, we recommend that you work with a qualified person who can facilitate a discussion and help write the document. This person can be a certified life planner, certified care manager, or someone with a social service, educational or journalistic background. In short, rely on someone who can listen well to the story you tell and who can write it in coherent, understandable terms.



A growing number of parents have developed a residence for their son or daughter ranging from a simple one bedroom condominium setting, an apartment with room-mates, to a home with paid care providers. In working with these parents, I've compiled the following observations regarding these experiences.

1 | FUTURE OF GOVERNMENT RESOURCES

The future of domestic spending on programs that provide support to individuals with disabilities is uncertain. On the federal level, there will be continuing efforts to reduce the federal deficit. Individuals with disabilities, recipients of Medicaid benefits and others who rely on government assistance for health care will face the threat of reductions in appropriations, elimination of some benefits and a conversion to Medicaid block grants. These threats are real. So in planning a residential future, significant reliance must be made on private funds. While we must continue to advocate to maintain and increase federal and state appropriations as well as work toward creating more cost-effective models to use government appropriations, families must not overly rely on the hope that government resources will be the sole support of their son or daughter in the future.

2 | IMPORTANCE OF STARTING EARLY WITH A PLAN

The parents who have successfully arranged an appropriate home for their son or daughter started planning one to three years before their son or daughter moved in. The reasons for planning early are self-evident. First, you need to develop consensus within the family about whether your plans make sense and to build an internally driven commitment within the family to keep moving forward. One very obvious trap is the Get-To-It trap. These are the ideas, plans and things that need to be investigated, performed and vetted in order to move forward, but you put them on your To-Do list. The problem is that many people never Get-To-It. These are the things that you'll get to ... someday. But the list grows and grows while life just happens. Covey has written about the critical importance of prioritizing those things in our life that at the moment are not urgent but that are very important. The key is to differentiate those things that are truly urgent and important from the crisis of the day or week that seems urgent but is not, in reality, all that important. My advice is to schedule some quiet time on a regular basis to write out your thoughts, talk about your plans with your spouse and important other people, and to conduct your due diligence. This can be an ongoing planning meeting for you and your family members, with invitations going out to others on an as-needed basis.

3 | THE USE OF LEVERAGE

Broadly speaking, leverage is creating more power through the creative use of resources. For instance, leverage can be three or four families coming together to pool their money to create more buying power so they can purchase a home more easily together than they could on their own. Some families may have more financial resources than others, while some others may have more time to contribute. Don't minimize the value of time that can be contributed. In one successful model, two families planned an arrangement in which one family purchased a house next to the other family, who did not have the financial capital to contribute toward the purchase of the house. But the family without the available capital had something as valuable as money; they had human capital. They lived next door and provided support to the two young adults living there. It worked. Also, many retirement plans can be leveraged through a loan. Repayments must be made at a marketable interest rate, but remember, you're replenishing your own retirement account by paying down the loan. You will need to check with your retirement plan administrator to see if this is possible with your particular plan. Finally, you should evaluate the advisability of refinancing your principal residence or taking out a home equity loan.

4 | THINGS CHANGE-BE FLEXIBLE

Where we live depends on many factors including the location of family and friends, our work, the type of environment we choose to live in and a host of other considerations. Things change. We downsize, we retire, we get divorced, etc. And major life events are often accompanied by a change in living environment. In most circumstances, real property in a trust or in a corporate real estate holding entity can be exchanged with very little difficulty to accommodate changes in the location of property.



5 | IDENTIFY HOUSING DOLLARS SEPARATE FROM SUPPORT AND SERVICE DOLLARS

The acquisition and regular maintenance of real estate can be budgeted and planned for in a fairly easy fashion. The source of funds to purchase may come from savings, a loan from a retirement account, a gift from family members, proceeds from a home equity loan, etc. The regular carrying cost of the home can be paid from anticipated rental income, a planned escrow account or other anticipated revenue. Consider creating an annual budget for estimated housing costs as a planning tool. Two important sources of government funding for residential support for individuals with disabilities are the Section 8 voucher program and, in Massachusetts, the Alternate Housing Voucher Program (AHVP). Both programs are administered through housing assistance agencies and local housing authorities. Applications for rental vouchers can be obtained and filed at local housing authorities. Even with an anticipated long waiting list, an application should be filed if there is a tangible possibility of your son or daughter moving out of your home. Under federal regulations governing the use and administration of Section 8 housing vouchers, a person with a disability who has been granted a voucher is entitled to a reasonable accommodation in how the voucher is used. This means that the customary “arms-length” requirements between landlord and tenant can be modified. So, a family owned or controlled rental unit can be leased to a family member with a disability who has a voucher. In some circumstances, a special needs trust can be the landlord and the beneficiary of the trust can be the tenant.

6 | KNOW THE SUPPORT AND SERVICE NEEDS OF INDIVIDUALS

A complete understanding of the service and support needs of each individual must be arrived at as part of the planning process. While this may seem obvious, there is one general tendency I’ve noticed over the years. Parents often overestimate their son’s or daughter’s daily living skills. Often, parents discount the value of a regular routine, the presence of familiar family members and the often overlooked presence of verbal and non-verbal cueing that is natural in a home environment. It may be worthwhile expense to retain the services of a qualified professional to assist you in accurately evaluating the level of services and supports your son or daughter as well as other prospective residents will need when they move in to their new home. Accurately assessing the service and support needs of each individual is essential in estimating the anticipated costs of meeting those needs through appropriate staffing your family members with invitations going out to others on an as-needed basis.

7 | IDENTIFY SUPPORT AND SERVICE DOLLARS

Obviously, if your son or daughter and other prospective residents are eligible for adult services from a state agency, you should speak with the appropriate person assigned to his or her case about your intentions. This person can be helpful in providing a realistic expectation about prioritization and allocation of resources. Also, personal care assistance (“PCA”) funded through the Division of Medical Assistance can be a source of support dollars. A determination of whether PCA is appropriate and the extent of the PCA support should be made as soon as possible. Finally, each resident’s SSI, Disabled Adult Child (DAC) benefits and other recurrent monthly income will be available to fund a portion of the supports to be provided. It is customary that 75% of the recurrent monthly income of each resident be paid in the form of a service fee. Also, for many families, privately paying for services and supports has become a daunting but necessary reality.

8 | IMPORTANCE OF GOOD ADVISORS

The activities of maintaining a home for a son or daughter with a disability can involve, for instance, the purchase of real estate, creating a landlord/tenant relationship, having service and supports provided on a regular basis by paid staff, maintenance and upkeep, etc. An attorney should be involved in many of these areas including selecting the appropriate legal entity to own the real estate, creating a sensible service agreement for settings that are non-DDS or non-DMH regulated, understanding and complying with applicable labor/employment practices, and identifying potential sources of liability and taking steps to minimize and/or avoid such liability. The skills and talents of experienced staff who can manage a residential setting can be a valuable asset. There are a number of highly skilled administrators with years of experience in managing residential services and supports for individuals with disabilities who are available to serve on either a short-term consulting or long-term management fee basis. You don’t have to reinvent the wheel! Of course, having a reliable handyman, plumber and electrician on speed-dial can save time and lower your blood pressure when the inevitable-yet unexpected-housekeeping crisis hits.

9 | INTEGRATION OF THE HOUSING MODEL INTO YOUR ESTATE PLAN

You must plan for how the home will be managed when you are unable to be involved due to death or disability. A comprehensive special needs plan is an essential part of developing a home for your son or daughter with a disability. The fundamental documents must provide for the distribution of assets to the appropriate persons and trusts in the proportions desired. Durable powers of attorney with critical Medicaid planning language and health care proxies are essential. The use of a special needs trust to hold assets for the benefit of a son or daughter with a disability to pay for future services and supports is the centerpiece of this plan. These essential documents must be coupled with a realistic financial plan adequate to provide for supplemental services and supports throughout the lifetime of a son or daughter with a disability.

10 | IMPORTANT PERSONAL QUALITIES: PATIENCE AND PERSISTENCE

There is no cookie-cutter approach to developing an effective and successful home for your son or daughter with a disability. It is easy to get disillusioned because solutions are slow to develop. There are many moving parts and some dead ends. The parents I've had the privilege to work with in these types of situations have demonstrated an enormous amount of patience and persistence. They share a common characteristic of expecting more from themselves than from anyone else, including the government. There is also a sense of "I know best" and "I'm going to keep trying." These personal characteristics of patience and persistence imbued with a sense of optimism are important to move from the vision of a home to a real home.



ABOUT THE AUTHOR



Frederick M. Misilo, Jr. is an attorney who concentrates his practice in special needs planning, elder law, trust and estate administration, and service advocacy. He chairs the Special Needs and Elder Law Practice Group at Fletcher Tilton PC, a Massachusetts law firm with offices in Framingham, Hyannis and Worcester. Attorney Misilo is also the department chair of the Trust and Estate Department and serves on the firm's Management Committee.

Attorney Misilo has been deeply involved in disability issues throughout his career. After graduating from college, Mr. Misilo worked in progressively responsible positions in community-based services for individuals with intellectual and developmental disabilities, including serving as the Executive Director of Harbor Area Community Services, Inc., in Boston, Massachusetts. Several years later he left the private practice of law for three years to serve as Deputy Commissioner of the Massachusetts Department of Developmental Services (1991-1994).

Attorney Misilo currently serves the Arc of the United States, Inc., as a member of the board of directors, the Legal Advocacy Committee, the Policy and Positions Committee and the Ad-hoc Committee on planned communities. Attorney Misilo also currently serves on the board of directors of the Cardinal Cushing Center, the Arc of Cape Cod and Fallon Community Health Plan, Inc.

Mr. Misilo is a past president of the Arc of Massachusetts, Inc. He also served on the Holden Board of Selectmen for nine years (three years as chairperson) and on the board of directors of the Worcester Regional Chamber of Commerce for eight years (three years as chairperson).

Among his awards, the Arc of Massachusetts presented him the Joseph Andrade Award for Leadership in 2011 and the Rose Pessin Memorial Award in 2012. The Arc of Cape Cod awarded him the Arc Angel of the Year Award in 2010.

The media regularly seeks Mr. Misilo's opinion on a wide range of issues relating to those with disabilities. As an example, Attorney Misilo provided technical assistance to and his advocacy work was featured in *Autism: Coming of Age*, a PBS documentary that addressed the challenges faced by individuals with autism and their families. This documentary was chosen by judges from CBS, NPR, ABC and the PBS NewsHour as the 2012 winner of the National Journalism Award from the National Institute of Health Care Management.

Mr. Misilo is a member of the National Academy of Elder Law Attorneys and a charter member of the Academy of Special Needs Planners. He holds a law degree from Suffolk University, a master's degree in education (administration, planning and social policy concentration) from Harvard University and a B.A. in individual studies from the University of Massachusetts at Amherst. He also has received the designation of Certified Trust and Financial Advisor (CFTA) from the Institute of Certified Bankers of the American Bankers Association.

ONLINE RESOURCES

American Association on Intellectual and Developmental Disabilities	www.aidd.org
Association of Developmental Disabilities Providers	www.addp.org
The Arc of Massachusetts, Inc.	www.arcmass.org
The Arc of the United States, Inc.	www.thearc.org
Department of Children & Families	www.mass.gov/dss
Department of Developmental Services	www.mass.gov/dds
Department of Education and Secondary Education	www.mass.gov/doe
Department of Health & Human Services	www.mass.gov/eohhs
Department of Housing & Community Development	www.mass.gov/dhcd
Department of Labor and Workforce Development	www.mass.gov/lwd
Department of Mental Health	www.mass.gov/dmh
Department of Public Health	www.mass.gov/dph
Department of Transitional Assistance	www.mass.gov/dta
Disabled Persons Protection Commission	www.mass.gov/dppc
Executive Office of Elder Affairs	www.mass.gov/elders
Families Organizing for Change	www.mfofc.org
Federation for Children with Special Needs	www.fcsn.org
Institute for Community Inclusion	www.communityinclusion.org
Mass. Association of 766 Approved Private Schools	www.spedschools.com
Mass. Bay Transportation Authority	www.mbta.com
Massachusetts Community Gateway	www.communitygateway.org
Mass. Commission for the Deaf & Hard of Hearing	www.state.ma.us/mcdhh
Mass. Developmental Disabilities Council	www.state.ma.us/mddc
MassHousing	www.mhfa.com
Mass. Office on Disability	www.state.ma.us/mod
Mass. Rehabilitation Commission	www.mass.gov/mrc
Mass. Society for the Prevention of Cruelty to Children	www.mspcc.org
Social Security Administration	www.ssa.gov
Statewide Head Injury Program	www.mass.gov/mrc/ship
The Association for Persons with Severe Handicaps	www.tash.org
United Cerebral Palsy Association	www.ucp.org

WE'RE HERE TO HELP

For additional free information on the issues covered in this handbook, in addition to helpful tools and articles, please visit our website.

www.fletcherilton.com

Fletcher Tilton PC
Attorneys at law

This material is intended to offer general information to clients and potential clients of the firm, which information is current to the best of our knowledge on the date indicated below. The information is general and should not be treated as specific legal advice applicable to a particular situation. Fletcher Tilton PC assumes no responsibility for any individual's reliance on the information disseminated unless, of course, that reliance is as a result of the firm's specific recommendation made to a client as part of our representation of the client. Please note that changes in the law occur and that information contained herein may need to be reverified from time to time to ensure it is still current. This information was last updated January, 2013.

WE CAN HELP

The attorneys at Fletcher Tilton PC are experienced in representing clients with special needs issues. We have extensive experience with special needs estate planning, guardianships and other less restrictive measures, DDS eligibility appeals, ISP appeals and supplemental needs trust management, as well as general advocacy for our clients. If you have a legal problem, we can assist you in getting it resolved.

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